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Butterfly Project-Helping Incarcerated Women Have Access to the Alabama Breast and Cervical Cancer Early Detection Program

Public Health Problem

In Alabama, 49,419 women between the ages of 40 and 64 were eligible to participate in the Alabama Breast and Cervical Cancer Early Detection Program (ABCCEDP) in 2003. Typically, only 25 percent of those eligible women participated in the program. Reaching women in rural areas and recruiting eligible women who have never heard of the program can be difficult. In response to such low participation, a health educator with the HIV/AIDS Division asked ABCCEDP to conduct a health promotion class at both of the women's state prisons. After the success with the state prisons, the program was expanded to county facilities. This experience revealed that the majority of incarcerated women had never heard about the screening program, and thus had not participated.

Taking Action

In January 2004, a partnership was formed among ABCCEDP, the AVON Foundation Breast Care Fund, and the Alabama Sheriffs' Association. The partnership, known as The Butterfly Project, educates women about the importance of early detection of breast and cervical cancers. Working with the county sheriffs' departments and state correctional facilities, the project staff transport incarcerated women for breast and cervical cancer screenings at their county health departments. As a result, more than 700 women have been educated and screened. One incarcerated woman shared her appreciation with the program after she found a mass and was later diagnosed with breast cancer. She is currently in treatment and is extremely grateful that the program motivated her to take care of herself.

Implications and Impact

The Butterfly Project has received national attention in its first year through the American Jail Association's magazine American Jails. ABCCEDP was invited to share details of The Butterfly Project at the association's annual conference and has subsequently received telephone calls from other states interested in developing similar programs. In addition to providing breast and cervical cancer information for female inmates, health educators are developing a videotape to teach women how to perform a breast self-exam and to increase cervical cancer awareness. The video will be broadcast nationally through the American Jail Association's satellite teaching network. Participating correctional facilities can use the educational message to teach incarcerated women the importance of early detection. The message also gives these women a sense of self-worth and empowerment as they learn steps to take care of themselves.



Colorado Advances Health Priorities by Constitutional Amendment

Public Health Problem

Chronic diseases, such as heart disease, stroke, and cancer, are the most prevalent, costly, and preventable of all health problems; however, securing resources to enable public health agencies to implement programs to prevent chronic disease is an ongoing challenge. State budgets continue to face shortfalls that limit the capacity of public health agencies to implement, sustain, and enhance chronic disease prevention programs. In Colorado, as in many other states, budget shortfalls have resulted in the re-allocation of funds from the Tobacco Master Settlement Agreement to support other needs. Because of diminishing resources, Colorado has been limited in its ability to fully implement public health programs designed to reduce the use of tobacco through prevention and cessation and to reduce the burden of chronic diseases through education and support of proven clinical preventive services for cancer and heart disease.

Taking Action

In November 2004, Colorado voters approved Amendment 35, a citizens' initiative that added "Tobacco Taxes for Health Related Purposes" to the State Constitution. As a result, on January 1, 2005, a new tax of 65 cents was added to the price of each pack of cigarettes. This new tax raises the Colorado tobacco excise tax to about the national average and generates about \$175 million per year in new revenues. The Amendment specifies that all of these new monies are to be used for health purposes. Most of the money will be used to subsidize health care for the uninsured, but 16 percent (about \$28 million per year) will be dedicated to tobacco control, and another 16 percent to cancer and cardiovascular disease prevention. The Amendment process assures that these new funds cannot be allocated for other purposes, so long-term strategies and programs can now be implemented to reduce the burden of cancer and cardiovascular disease in Colorado.

The Colorado Cancer Coalition, a broad consortium of organizations and individuals with interests in the prevention and control of cancer in Colorado, played an integral role in achieving this outcome. Working along with its partners, the state's Comprehensive Cancer Program supplied critical data to the Coalition for determining objectives, goals, and priorities in cancer prevention and control to reduce the burden of cancer in Colorado. Because a Colorado Cancer Plan had been developed and publicized, the drafters of Amendment 35 were able to specify earmarked funds (about \$28 million per year) to support the implementation of the plan.

Implications and Impact

The Colorado Cancer Plan is the cornerstone of the Colorado Cancer Coalition. The vital role of the plan in the earmarking of new tobacco tax funds for cancer control in Colorado underscores the value of having a statewide action plan that is collaboratively developed and collectively supported. Equipped with a data-based state cancer plan, partners are better prepared to address their state's specific cancer problems as well as develop strategies to gather support for cancer control. Citizen-initiated constitutional amendment processes are possible in many other states, where cancer control programs could also be funded by designated new tobacco taxes.

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Assessing Quality of Life at the End of Life in Maine Veterans' Homes

Public Health Problem

In 2002, Last Acts, a national coalition to improve care and caring near the end of life, published Means to a Better End: A Report on Dying in America Today. This document rated each of the 50 states and the District of Columbia on eight criteria as a basis for assessing end-of-life care. The criteria included: 1) advanced care planning; 2) dying at home; 3) use of hospice care; 4) hospital-based palliative care services; 5) over-aggressive care; 6) pain management in nursing homes; 7) pain management policies; and 8) availability of trained palliative care staff. Maine received a "D" or lower rating in four of those eight areas, indicating that there was significant room for improvement in end-of-life care in Maine.

Taking Action

In 2003, the Maine Comprehensive Cancer Control Program, in conjunction with the Maine Hospice Council and the Maine Veterans' Homes (MVH), assessed the end-of-life care in MVH facilities relative to existing national data and palliative care standards. Retrospective chart audits were conducted at MVH facilities in which residents died with cancer diagnoses between 2000 and 2003. A standardized data collection instrument was used to assess indicators of quality of life (QOL), including resident demographic information, diagnosis, family issues, site of death, symptom management, and palliative care. Residents' wishes relating to Do Not Resuscitate orders were consistently respected. Invasive-type treatment was found in the last weeks of life in 35 percent of cases reviewed. Up to 67 percent of the study population reported experiencing some pain. Opioids for pain management were given to 87 percent of residents in the last 48 hours of life. Documentation of the religious and spiritual preferences of MVH residents was lacking overall. The number of documented clergy visits was very low. Only 14 percent of the total resident population reviewed were referred to local hospice programs.

Implications and Impact

The results show that there is much room for improvement in Maine for pain management, advanced directive/advanced care planning, clergy visitations, and documentation of patient religious and spiritual preferences, as well as for increased use of community-based hospice programs. Staff education and training in pain management, end-of-life care, and documentation of patient needs and preferences could be improved. Additionally, standardization of care practices in the art of providing excellence in end-of-life care may be useful. This project could serve as a model for all states that are working on end-of-life issues through their comprehensive cancer control programs. Not only does it serve as a model for assessing QOL at the end of life, it also creates opportunities to work with non-traditional partners, such as veterans' homes, the state hospice association, and community hospice agencies. QOL at the end of life is an important concern for many cancer patients. There is a huge opportunity to improve the systems and manner in which end-of-life care is given.



Korean Outreach Workers Reduce Screening Barriers for Korean Women

Public Health Problem

In 2004, an estimated 4,090 Maryland women will be diagnosed with breast cancer and approximately 760 women will die of the disease. About 220 women in Maryland will be diagnosed with cervical cancer in 2004. A community study of Korean-Americans found that only 10 percent of respondents aged 40 to 69 reported ever having a mammogram, and 54.8 percent of same-aged women in a corresponding study reported ever having a Papanicolaou (Pap) test. According to the U.S. Census, from 1990 to 2000 the Korean population increased from 2,369 to 6,188 in Howard County, Maryland, and from 4,893 to 5,249 in Baltimore County - increases of 161 percent and 7.2 percent, respectively.

Taking Action

Twenty-two local health departments and two hospitals are responsible for implementing the Maryland Breast and Cervical Cancer Program (BCCP). Of those, two local health department BCCPs demonstrate success in recruiting Korean women into the program by employing bilingual Korean outreach workers. Outreach workers that are from the specific population are effective in promoting screening for early detection of breast and cervical cancer by addressing the cultural and language barriers. A variety of factors, including cultural differences, language barriers, transportation barriers, and misperceptions about their cancer risk, contribute to Korean women never or rarely having been screened for breast and cervical cancer. The bilingual Korean outreach workers use a combination of strategies including one-to-one recruitment, public service announcements (PSAs) in a Korean newspaper, outreach to Korean grocery stores, and word of mouth within the Korean community. Additionally, Korean outreach workers translate during screening appointments, case management, and recall.

Implications and Impact

The BCCPs in Baltimore and Howard Counties demonstrate the impact of using bilingual Korean outreach workers to reduce cultural barriers and recruit Korean women for screening. In Baltimore County from January 1, 1992, to August 9, 2000, a total of 83 Asian women were screened, an average of about 9 per year. A Korean outreach worker was hired on August 10, 2000. From August 10, 2000, to April 4, 2003, 225 Asian women were screened, or about 90 per year. This is a ten-fold increase in the average per-year screening of Asian women. About 75 percent (168) were identified as Korean. In fiscal year 2003, 20.4 percent of patient visits in Howard County's Breast and Cervical Cancer Screening Program were for Korean women, compared to only 10 percent in 1997 before a Korean outreach worker was hired. The use of bilingual Korean outreach workers has demonstrated success in decreasing access barriers and enabled many high-risk Korean women to obtain breast and cervical cancer screening that they may not have received otherwise.

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Women's Health Screening Events in Southeast Missouri

Public Health Problem

Southeast Missouri is a large rural area with limited medical services. Low socioeconomic status, as well as high insurance premiums and deductibles, have prevented underserved women from receiving breast and cervical cancer screening and diagnostic services.

Taking Action

In 2004, four different events were held in eight rural locations in Southeast Missouri. BJH brought staff and a mobile mammography unit from St. Louis to work with local SMHW providers. These Women's Health Days were advertised through the media, church bulletins, flyers, and word of mouth.

A task force, which was created to help alleviate this burden, collaborated with Barnes Jewish Hospital (BJH) to help increase awareness about the availability of screening services through the state's Show Me Healthy Women (SMHW) program. The task force enlisted the aid of local church groups; the American Cancer Society; cancer support groups; local radio stations and newspapers; and Caring Communities, a grassroots coalition that provides resources for community members. Special women's health screening events, scheduled for one to three days each, were planned to assure free mammograms, free clinical breast examinations, free Papanicolaou (Pap) screening, and instruction in breast self-exams for SMHW-eligible women.

Implications and Impact

Through the women's health screening events, a total of 459 women have received screening mammograms, clinical breast examinations, and instruction in self-breast exams, as well as 157 Pap tests. All abnormal findings were followed, and clients were referred for care as needed. Eleven breast cancers were found and these women were enrolled in BCCPT. Data on follow-up screenings will be available next year when the project is continued. Outcomes from this project are being prepared to share with other SMHW case managers for use in other areas of the state. The Missouri Cancer Consortium (MCC), which is developing a statewide comprehensive cancer control plan, will use this program's materials, approaches, and evaluation methods as a model for promoting breast and cervical cancer control screening and diagnostic services for underserved women in Missouri.



Using Electronic Pathology Reporting to Improve Case Ascertainment

Public Health Problem

Having complete and accurate cancer data is important to understanding the burden of cancer. Prior to collecting and analyzing cancer morbidity and mortality data for the year 2000, the Nevada Central Cancer Registry (NCCR) was unable to provide complete reporting of cancer cases. Consequently, Nevada did not meet the completeness standards required for certification by the North American Association of Central Cancer Registries (NAACCR).

Taking Action

NCCR believed it had captured all the cancer cases that were diagnosed or treated in an inpatient facility (e.g., hospital), but fell short in identifying cancer cases that were diagnosed or treated in an outpatient setting (e.g., doctors' offices, surgi-centers). In order to capture cancer cases in the outpatient setting, NCCR electronically processed more than 10,000 pathology reports and was able to identify more than 2,000 new cancer cases. NCCR increased reporting of prostate, breast, melanoma, and bladder cancers by 12.2 percent. These are forms of cancer that are typically diagnosed and treated in an outpatient setting. Of the 1,512 breast cancers reported, 22.6 percent were reported from "path only" (i.e., the case was identified from a pathology report and no other source) cases accounting for an 8.7 percent increase in overall breast cancer reporting. Of the 435 cases of malignant melanoma skin cancers reported, 46 percent were from "path only" cases, accounting for an 89 percent increase in overall malignant melanoma reporting. Of the 1,319 prostate cancers reported, 22.4 percent were reported from "path only" cases. This accounted for an 8.3 percent increase in overall prostate cancer reporting.

Implications and Impact

By electronically processing pathology reports, NCCR was able to achieve more than 95 percent complete case ascertainment for 2000 and 2001 data and thus achieved "Gold" Certification from NAACCR. In 1997, NAACCR instituted a program that annually reviews member registries for their ability to produce complete, accurate, and timely data. The registry certification program then recognizes those registries meeting the highest standards of data quality with Gold or Silver recognition certificates for each data year. This achievement allowed the State of Nevada to produce Cancer Report on Nevada, which included epidemiological analysis that statewide cancer prevention and intervention programs can use to target appropriate services. Moreover, Nevada is now included in United States Cancer Statistics, which is produced and disseminated by the Centers for Disease Control and Prevention. Finally, NCCR was recently recognized as "Outstanding Program of the Year" by the State of Nevada Health Division and the program manager was awarded "Outstanding Employee of the Year."

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Working With Wisconsin's Indian Health Service Clinics to Improve Race Classification on Cancer Reports for Native Americans

Public Health Problem

The Wisconsin Cancer Reporting System (WCRS) collects and maintains data on all Wisconsin residents who are diagnosed with cancer - approximately 26,000 new cases per year. Wisconsin's cancer morbidity and mortality rates are calculated annually to assess the state's cancer burden. Based on findings from studies conducted in other states that showed underreporting and misclassification of Native American/Native Indian (NA/NI) populations, WCRS was concerned that NA/NIs might be underreported or misclassified in its database, and consequently misrepresented in the burden assessments.

Taking Action

WCRS collaborated with CDC and the Indian Health Service (IHS) to link 17 years of registry data with IHS enrollment lists. The results showed that 37 percent of the cancer cases matched to IHS enrollees were misclassified as non-Native American. WCRS also participated in the Spirit of EAGLES Building Cancer Surveillance Capacity project, a collaboration among the Wisconsin Tribal Health Directors Association, the Great Lakes Inter-Tribal Council, the Mayo Clinic Cancer Center, the University of Wisconsin Comprehensive Cancer Center (UWCCC), and WCRS. Data on cancers diagnosed in 2001 at Wisconsin's 12 tribal clinics and one suburban clinic that serve the Native American population were collected directly from those facilities and matched against the WCRS registry. At the time of the study, only 50 percent of the cases had been reported by non-IHS facilities, and of those that had been reported, 25 percent were misclassified as non-Native American.

In light of those results, WCRS is now collaborating with UWCCC and Wisconsin's tribal clinics to collect data directly from those clinics on a routine basis, starting with 2004 cases, to ensure stable and accurate reporting of cancers to WCRS for the Native American population in Wisconsin. A simplified reporting form and protocols have been established and will be implemented later this year.

Implications and Impact

Accurate race reporting is crucial for monitoring health status and planning interventions for reducing cancer morbidity and mortality in Wisconsin. This collaboration will improve the data collected on the NA/NI population in Wisconsin, allowing for more accurate analysis of the cancer patterns within this population (type of cancer, how far it has spread within the body, types of treatments being offered, etc.). This model can be adopted by cancer registries in other states that may have similar challenges due to underreporting or racial misclassification.